



WHAT WE NEED IN HEALTH CARE

MINIMUM ELEMENTS REQUIRED FOR PEOPLE WITH BLEEDING DISORDERS

Necessary Consumer Protections / Private Insurance

Protect people who have pre-existing conditions.

Bleeding disorders are genetic conditions that are present at birth. Meaningful health coverage is indispensable for people who live with these conditions. We know from long experience that people with bleeding disorders and other chronic conditions will be unable to buy individual coverage unless health plans are prohibited from rejecting, or otherwise discriminating against, people on the basis of their health. Medical underwriting – setting premiums on the basis of patients’ health status – also blocks access to health insurance for those who most need it, and also must be prohibited.

Prohibit annual and lifetime limits on health plan benefits.

Many individuals living with a bleeding disorder will routinely use \$250,000 to \$1 million worth of medication each year, for life, depending on the severity of their individual conditions. An adult with hemophilia could hit a \$1 million cap in two or three years; an individual experiencing inhibitors or other complications could reach that cap even faster. The Affordable Care Act (ACA) ban on annual and lifetime limits is thus a critical protection for bleeding disorders patients against losing their insurance due to “maxing out” annual or lifetime limits on benefits.

Assure meaningful coverage/appropriate scope of health benefits (cover prescription drugs, necessary providers of services).

Insurance is not meaningful unless it covers the services and products people need in order to stay healthy. Prior to enactment of the ACA, too many individuals with bleeding disorders had health plans that excluded coverage for the medications and/or services necessary to control or prevent joint- and life-threatening bleeding episodes. This kind of under-insurance is functionally equivalent to a complete lack of insurance. Standards for what health plans must cover (prescription drugs, chronic disease management, emergency care, etc.) are critical in order for insurance to be meaningful.

Limit out-of-pocket costs.

As more health plans shift costs to consumers, it is vitally important that patients are protected against unlimited out-of-pocket spending (copays, deductibles, and coinsurance) on essential health benefits. People living with hemophilia and other bleeding disorders rely on costly medications in order to maintain their health, and most will hit their out-of-pocket maximums every year, for life. This hefty burden – “financial toxicity” – can affect adherence to treatment, health outcomes, and overall quality of life. People with bleeding disorders need to be able to afford their health- and life- sustaining treatments.



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Keep coverage for children up to 26 years old.

Bleeding disorders are expensive chronic conditions that come with a high, life-long price tag. As noted, people with bleeding disorders routinely hit their out-of-pocket spending maximums each year. Bearing these catastrophic costs (on top of the premium costs to purchase insurance in the first place) is extremely difficult for almost anyone – but is almost impossible for many young people early in their work lives. Staying on their parents' insurance until age 26 allows young people with bleeding disorders time to become established in their careers before they have to shoulder the weighty burden of paying the year-in, year-out costs of their health care.

Protect market stability; preserve affordable access to insurance for those who most rely on it.

Federal agencies and some States are considering a range of proposals to expand the availability of non-ACA compliant health plans: association health plans, short-term limited duration health plans, and more. This course of action threatens market stability and continued access to comprehensive health insurance. Allowing the sale of cheaper, non-compliant plans would likely draw younger and healthier people away from the traditional individual and small group markets. This skewing of the risk pool would drive up premiums for comprehensive insurance: the ACA-compliant market would increasingly comprise only enrollees with expensive health needs (such as hemophilia) who can't go without robust health coverage. Year by year, premiums would rise ever higher, the pool of enrollees would shrink further, and insurers would abandon unprofitable markets. Law-makers should reject these destabilizing proposals; they should reject the idea of lowering premiums for healthy consumers at the expense of people who need robust coverage.

Oppose high risk pools.

The bleeding disorders community has long experience with high risk pools and their many shortcomings. High risk pools were used in 35 states prior to enactment of the ACA to cover people with pre-existing conditions. These pools generally offered limited coverage, with high deductibles and low annual and lifetime coverage caps. Premiums could be prohibitively expensive (often 200% or more of the prevailing rate in the individual market) and many states were unable to make up the resulting shortfall in funding when premiums and deductibles didn't cover costs of care for the high-need enrollees. Because so many high risk pools were chronically underfunded, they implemented enrollment caps and waiting lists that excluded many (sometimes most) of the individuals who applied for coverage. Thirty-three states imposed annual and/or lifetime caps on pool participants, and some pools implemented tight restrictions on the scope of coverage – including pre-existing condition exclusions, the very problem they were designed to remedy.



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Keep Medicaid Expansion For Low Income Adults, Maintain Federal Medicaid Funding, And Avoid Overly Restrictive Limits On Eligibility

Bleeding disorders are treatable and individuals can lead healthy and productive lives despite the disorder, but treatment comes at an extremely high cost. Low income individuals and families coping with bleeding disorders are at great risk if they lack employer-sponsored health insurance and cannot afford policies in the non-group market. States that expand Medicaid provide an absolutely essential safety net for this segment of the bleeding disorders population. The federal government must maintain its commitment to states so they can continue to serve vulnerable populations. States should reject draconian restrictions on eligibility for Medicaid (e.g., work requirements, or term limits on periods of eligibility) which create administrative obstacles to coverage and block access to care for people with serious health issues.